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ABSTRACT

This resource guide provides an annotated list of publications on parenting and caring for children with special health needs, along with a list of organizations that can provide additional information. The list of publications includes 21 books, reports, bibliographies, directories, and periodicals produced between 1982 and 1988. Bibliographic information is provided as well as annotations and availability information. The list of organizations offers names, addresses, telephone numbers, and brief descriptive information for 19 groups, including parent support groups, professional organizations, research and service organizations, information services, advocacy groups, and coalitions. (JDD)

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Children with Special Health Needs

A Resource Guide

National Center for Education in Maternal and Child Health

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Children with Special Health Needs

A Resource Guide

March 1989

Produced and published by:
The National Center for Education in Maternal and Child Health (NCEMCH)
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NCEMCH provides information services to organizations, agencies, and individuals with maternal and child health interests. NCEMCH was established in 1982 at Georgetown University, within the Department of Obstetrics and Gynecology. NCEMCH is primarily funded by the U.S. Department of Health and Human Services through its Bureau of Maternal and Child Health and Resources Development.

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CHILDREN WITH SPECIAL HEALTH NEEDS

Children with special health needs have congenital or acquired conditions that affect physical growth and development and require extended or sequential services. Recent advances in medical care and technology have allowed disabled or seriously ill children to survive longer than they would have in the past, bringing up new issues regarding care and services for these children. In addition, recent legislation has both reflected and encouraged trends toward family-centered, community-based care for special needs children. Parenting and caring for a child with special health needs presents some special challenges, and both the families of these children and the health professionals who work with them need information and support as they work to provide the best possible care for these special needs children.

As part of an effort to provide information and educational materials on maternal and child health topics, the National Center for Education in Maternal and Child Health (NCEMCH) has prepared this resource guide on children with special health needs. Included in this resource guide are an annotated listing of current publications and a list of organizations that can provide additional information. Federal and state government maternal and child health agencies may also be able to provide further information.

Federal maternal and child health services are provided through Title V of the Social Security Act, which is administered by the Office of Maternal and Child Health (within the Bureau of Maternal and Child Health and Resources Development, Public Health Service, Department of Health and Human Services). Eighty-five percent of federal Title V monies are allocated to the states in block grant form. The remaining 15% are awarded on a competitive basis to support Special Projects of Regional and National Significance (SPRANS). The purpose of the SPRANS program is to support projects relating to maternal and child health services or services for children with special health needs which show promise of making a substantial contribution to the advancement of such services. NCEMCH can provide further information about particular SPRANS, or about groups of projects on a particular topic.

At the state level, leadership for maternal and child health services, including services for children with special health needs, is provided through the official state health agency. (In 11 states, however, the programs for children with special health needs are administered by agencies and/or institutions other than the state health agency.) These agencies use federal block grant monies as well as state and, in some cases, local funds to assure access to quality maternal and child health services, promote the health of mothers and children, and provide assistance to children with special health needs. For additional information on this topic, you might wish to contact the Director of Maternal and Child Health (MCH) and/or the Director of Programs for Children with Special Health Needs (CSHN—formerly Crippled Children's Services) in your state. The names and addresses of state MCH and CSHN Directors can be obtained from NCEMCH.

PUBLICATIONS

The following is a list of some of the most recent publications that address children with special health needs. Copies of these publications may be available in local libraries or bookstores and are also available directly from the publisher. This is by no means a comprehensive list but merely a sample of current literature.

The exceptional parent. 605 Commonwealth Avenue, Boston, MA 02115.

This magazine is directed towards parents and professionals. It covers all disabilities, with an emphasis on education, advocacy, and care. (Published eight times each year.)

Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull, A. P. (1986). *Meeting the challenge of disability or chronic illness: A family guide*. Baltimore, MD: Paul H. Brookes Publishing Co.

This book focuses on coping skills and the process of problem solving. The purpose of the book is to provide families with the tools needed to tap inner sources of strength in dealing with difficult circumstances. Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285.

Healy, A., Keesee, P. D., & Smith, B. S. (1985). *Early services for children with special needs: Transactions for family support*. Iowa City, IA: The University of Iowa.

This book, which was written under a grant from the Office of Maternal and Child Health, is intended to be read by both parents and professionals concerned with special needs children. It attempts to help strengthen the link between the knowledge base and what is actually practiced in early intervention programs by outlining what is known about at-risk and disabled children and their families that should influence efforts to meet their special needs, by discussing the barriers to translating this knowledge into program practices, and by describing concrete steps that can be taken to improve this translation process. An annotated bibliography is included. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

Hobbs, N. & Perrin, J. M. (1985). *Issues in the care of children with chronic illness*. San Francisco, CA: Jossey-Bass Publishers.

The forty-two chapters of this book were commissioned for the Vanderbilt University study of chronically ill children and the services they require. This book provides guidance to anyone wishing to explore in depth the policy issues and options in the delivery of services to children with special health needs and their families. Available from Jossey-Bass Publishers, 433 California Street, San Francisco, CA 94104.

Hobbs, N., Perrin, J. M., & Ireys, H. T. (1985). *Chronically ill children and their families*. San Francisco, CA: Jossey-Bass Publishers.

This work is the culmination of the landmark Vanderbilt University study of ways to improve the lives of chronically ill children. It was written in hopes of assisting parents and professionals by defining the problem of finding and organizing information on chronic illness; by examining the strengths and weaknesses in current patterns of care, financing, professional training, and research; and by analyzing various policy options. Available from Jossey-Bass Publishers, 433 California Street, San Francisco, CA 94104.

Jones, M. (1985). *A manual and sourcebook for parents and professionals: Home care for the chronically ill or disabled child.* New York, NY: Harper & Row Publishers Inc.

This book provides information for parents and professionals on home care of chronically ill children. Practical suggestions are offered to assist in meeting the medical, educational, and social needs of the ill child. Available from Harper & Row Publishers, Inc., 10 East 53rd Street, New York, NY 10022.

Lapham, E.V., & Shevlin, K.M. (eds.) (1986). *The Impact of Chronic Illness on Psychosocial Stages of Human Development.* Washington, DC: The National Center for Education in Maternal and Child Health.

This book discusses the psychosocial impact of chronic illness in the context of the eight stages of human development described by Erik Erikson. Available for $12 from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

Meyer, D. J., Vadasy, P. F., & Fewell, R. R. (1985). *Siblings living with a brother or sister with special needs: A book for sibs.* Seattle, WA: University of Washington Press.

This guide book helps siblings of children with special health needs sort out and deal with their many and mixed feelings. Available from the University of Washington Press, P.O. Box C50096, Seattle, WA 98145.

National Center for Clinical Infant Programs. (1985). *Equals in this partnership: Parents of disabled and at-risk infants and toddlers speak to professionals.* Washington, DC: National Center for Clinical Infant Programs.

Produced through a grant from the Office of Maternal and Child Health, this publication grew out of a 1984 conference on comprehensive approaches to disabled and at-risk infants, toddlers and their families. The speeches of five parents and two professionals from the conference are included. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

National Center for Education in Maternal and Child Health. (1985). *Comprehensive clinical genetic services centers - A national directory.* Washington, DC: National Center for Education in Maternal and Child Health.

This directory lists over 200 centers which provide comprehensive diagnostic services, medical management, counseling, and follow-up for individuals affected by genetic disorders. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

National Center for Education in Maternal and Child Health. (1988). *Office of Maternal and Child Health active projects FY '88 - An annotated listing.* Washington, DC: National Center for Education in Maternal and Child Health.

This book identifies and briefly summarizes almost 500 active Special Projects of Regional and National Significance (SPRANS), including projects that deal with children with special health needs. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

National Center for Education in Maternal and Child Health. (1988). *Resources for clergy in human genetic problems: A selected bibliography.* Washington, DC: National Center for Education in Maternal and Child Health.

This bibliography provides an annotated list of resources useful to clergy who wish to counsel and support persons with particular genetic concerns. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

National Center for Education in Maternal and Child Health. (1988). *Starting early: A guide to federal resources in maternal and child health*. Washington, DC: National Center for Education in Maternal and Child Health.

This resource directory includes an annotated listing of over 80 federal agencies and information centers, a description of more than 500 publications and audiovisual materials, and a directory of federal, regional, and state maternal and child health programs. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

Salisbury, C. & Intagliata, J. (1986). *Respite care: Support for persons with developmental disabilities and their families*. Baltimore, MD: Paul H. Brookes Publishing Co.

This book is for families who require respite care for a member with a disability. It provides many answers to the most important questions about respite care and is divided into three major sections: rationale and need for respite services; issues and models for delivering respite services; and evaluating respite services. Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285.

Schleifer, M. & Klein, S. (1985). *The disabled child and the family: An exceptional parent reader*. Boston, MA: The Exceptional Parent Press.

This book provides practical information and guidance for those who are involved in promoting the growth and development of children with disabilities. It consists of articles on such topics as the implementation of laws, the family, growth and development of the disabled child, technology, and resources. Available from Exceptional Parent Press, 605 Commonwealth Avenue, Boston, MA 02215.

Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). *Family-centered care for children with special health care needs*. Washington, DC: Association for the Care of Children's Health.

This book discusses the elements of family-centered care, reviews the research in this area, and provides checklists for implementing family-centered care. In addition, family-centered care technical assistance, programs, and audiovisual and written materials are listed. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC 20057.

Simons, R. (1987). *After the tears: Parents talk about raising a child with a disability*. New York, NY: Harcourt Brace Jovanovich.

Commissioned by the Children's Museum of Denver, Colorado, the author interviewed parents of disabled children. The book recounts the experiences of these parents and describes the stages families go through as they rear their special needs child. Available from Harcourt Brace Jovanovich, 111 Fifth Avenue, New York, NY 10003.

Thompson, C. E. (1986). *Raising a handicapped child: A helpful guide for parents of the physically disabled*. New York, NY: William Morrow & Company, Inc.

This book addresses many common parental concerns that arise in caring for a disabled child or adolescent. Helpful appendices include a list of private and government agencies that offer help to families and a list of recreational facilities throughout the United States that are accessible to disabled children. Available from William Morrow & Co., Inc., 105 Madison Avenue, New York, NY 10016.

U. S. Department of Health and Human Services. (1982). *Report of the Surgeon General's workshop on children with handicaps and their families.* Rockville, MD: U.S. Department of Health and Human Services.

The Surgeon General's Workshop on Children with Handicaps and their Families was convened to seek out ways to lessen the handicaps imposed on disabled children and to promote child and family self-sufficiency and autonomy. Those attending the workshop concentrated on the severe, specific problems of the ventilator-dependent child, and the findings for this prototype were extrapolated for their implications for all handicapped children. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC, 20057.

U. S. Department of Health and Human Services. (1987). *Report of the Surgeon General's workshop on children with HIV infection and their families.* Rockville, MD: U.S. Department of Health and Human Services.

The purpose of this workshop was to summarize the current knowledge about AIDS in children and to make recommendations about future directions in research, prevention, and amelioration of the effects of pediatric AIDS. This report includes excerpts from the presentations at the conference, work group recommendations, and the response of the Surgeon General. Appendices include guidelines for management of HIV, the CDC classification system for HIV infection in children, and a report on education and foster care for children infected with HIV. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC, 20057.

U. S. Department of Health and Human Services. (1987). *Surgeon General's report: Children with special health care needs - Campaign '87.* Rockville, MD: U.S. Department of Health and Human Services.

This report focuses on a family-centered, community-based approach to health care for special needs children and outlines seven "action steps" which are aimed at improving access to care and the quality of life for all children with special health needs and their families. Available from the National Maternal and Child Health Clearinghouse, 38th and R Streets, NW, Washington, DC, 20057.

SELECTED SOURCES OF ADDITIONAL INFORMATION

Alliance of Genetic Support Groups
38th and R Streets, NW
Washington, DC 20057
(202) 625-7853

The Alliance is a coalition of voluntary organizations and professionals and is dedicated to fostering a partnership among consumers and professionals in order to enhance education and services for and represent the needs of families and individuals affected by genetic disorders.

Association for the Care of Children's Health (ACCH)
3615 Wisconsin Avenue, NW
Washington, DC 20016
(202) 244-1801

This is a non-profit, international organization of health professionals and parents who are dedicated to the well being of children and their families in all health care settings. Publications include many titles on chronically ill and hospitalized children as well as a newsletter, *ACCH Network*.

Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, NE
Seattle, WA 98115
(206) 523-8446

TASH is an international organization of over 6700 members who are concerned with the issues of human dignity, education, and independence for individuals with physical disabilities and profound mental retardation. Publications are available, and an information department answers all requests for information and referrals.

Center on Human Policy
Syracuse University
724 Comstock Avenue
Syracuse, NY 13244-4230
(315) 443-3851

This advocacy and research organization deals with issues related to the rights of people with disabilities to be integrated into educational, vocational, rehabilitative, and residential services.

Children's Hospice International
1101 King Street, Suite 131
Alexandria, VA 22314
(703) 684-0330

This organization supports health care agencies that treat terminally ill children and their families. It coordinates support systems for parents and siblings of children experiencing serious illness and for families who have experienced the sudden loss of a child through accident or violence. Children's Hospice International also acts as a clearinghouse for information on these issues.

Coordinating Council for Handicapped Children
20 East Jackson Boulevard, Room 900
Chicago, IL 60604
(312) 939-3513

This organization is a coalition of parent and professional organizations which publishes manuals, pamphlets, fact sheets, and newsletters, and serves as an information and referral resource.

Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

This organization acts as an information service for teachers, administrators, students, parents, and others concerned with the education of handicapped and gifted children. CEC is dedicated to advancing the education of exceptional children and youth.

Federation for Children with Special Needs
312 Stuart Street, Second Floor
Boston, MA 02116
(617) 482-2915

The federation is organized as a coalition of parent groups representing children with a variety of disabilities. They operate a parent information center which offers a variety of services to parents, parent groups, and others concerned with children with special needs.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

The March of Dimes supports research, medical services, and public and professional education aimed at the prevention of birth defects. Publications and audiovisuals are available.

National Center for Clinical Infant Programs (NCCIP)
733 15th Street, NW
Suite 912
Washington, DC 20005
(202) 347-0308

The NCCIP works to facilitate optimal health, mental health, and development for children through preventive clinical approaches in the earliest years of life. Activities include a fellowship program, training programs and institutes, and many publications for health care professionals and consumers. *Zero to Three*, the bulletin of the NCCIP, is published five times per year and addresses issues involved in parenting disabled, chronically ill, or high-risk infants.

National Easter Seal Society
2023 West Ogden Avenue
Chicago IL 60612
(312) 243-8400 (Voice); (312) 243-8880 (TDD)

The National Easter Seal Society provides rehabilitation services to persons with disabilities. Member groups provide programs which include medical or vocational rehabilitation facilities, recreation, housing, transportation, equipment loans, public education, advocacy, and other services for the prevention and treatment of disabling conditions.

National Information Center for Children and Youth with Handicaps (NICHCY)
P.O. Box 1492
Washington, DC 20013
(703) 893-6061

NICHCY is a free information service that assists parents, educators, caregivers, and others in ensuring that all children and youth with disabilities have a better opportunity to reach their fullest potential. NICHCY provides personal responses to specific questions, referrals to other organizations, information packets, publications, and technical assistance to parent and professional groups.

National Maternal and Child Health Resource Center
College of Law Building
The University of Iowa
Iowa City, IA 52242
(319) 335-9067

The Resource Center is a non-profit organization which promotes the improvement of health and related services for children with special health needs. The Resource Center maintains an information clearinghouse, conducts research, provides technical assistance, and is involved in planning and implementing education and training programs.

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812
(203) 746-6518

NORD is a coalition of voluntary health agencies, medical researchers, and private citizens dedicated to the interests of individuals with rare disorders. Among its goals are educating the public on the existence and treatment of rare disorders, fostering communication between rare disease voluntary agencies and government bodies, and advocating for people with rare disorders who are not otherwise represented.

National Organization on Disability (NOD)
910 16th Street, NW
Suite 600
Washington, DC 20006
(202) 293-5960; (202) 293-5968 (TDD)

NOD encourages organizations, corporations, and others to support local efforts and offer technical assistance toward integrating citizens with disabilities into community life. Annual awards are given to organizations for progress made toward integrating these citizens into the community.

National Parent CHAIN, Inc.
90 East Wilson Bridge Road
Suite 297
Worthington, OH 43085
(614) 431-1911 (Voice/TDD)

This is a coalition of parents, disabled consumers, and professional organizations. They provide information sharing and networking services in the areas of parent training programs, local parent and family support services, and assistance to parents of newly diagnosed disabled infants and children.

Parentele
5538 North Pennsylvania Street
Indianapolis, IN 46220
(317) 259-1654

Parentele is a national coalition created and operated by volunteer parents and friends of persons with disabilities. Its purpose is to share information about all areas that affect the lives of those who have disabilities.

Sibling Information Network
Connecticut's University Affiliated Program on Developmental Disabilities
University of Connecticut
249 Glenbrook Road
Storrs, CT 06268
(203) 486-3783

The Network serves as a clearinghouse for information, ideas, projects, literature, and research regarding siblings and other issues related to the needs of families with members who have special health needs.

Sick Kids (need) Involved People, Inc. (SKIP)
216 Newport Drive
Severna Park, MD 21146
(301) 647-0164

This is a national education resource and support organization that promotes specialized pediatric home care for medically fragile children. It provides information, education, and support over the telephone and through group meetings.